



Abstract

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PI Title:

Project Title: NATURAL HISTORY OF END OF LIFE DECISION MAKING

Abstract: *Over twenty years ago, in response to a medical culture characterized by paternalistic over-treatment, bio-ethicists and legal scholars promoted a model of end-of-life decision making based upon respect for patient autonomy. Empirical observations however, suggest that the Autonomy Model is only preferred by a segment of the population. Also, this model may not account fully for the complexity of end-of-life care, including cultural and ethnic differences in health care decision making and the important roles that family and religious communities play in supporting patients at the end of life. The purpose of this study is to use quantitative hypothesis testing and qualitative analysis to construct and test a model of end-of-life decision making with a focus on the decision control preferences of patients with terminal illnesses. This information will provide an in-depth understanding of the natural history of end-of-life decision making and can be used to enhance patient/family provider communication and provide health care consistent with patient/family values. We have modified the Decision Control Preference Scale of Degner and Sloan (1992) to measure the amount of control over end-of-life decisions that patients prefer to retain or place with the physician and/or family. Decision control preferences will be examined every three months for two years in 101 patients with terminal illnesses who have a prognosis of approximately two years of life. Patients will be followed from early in the diagnostic period until death. The illnesses selected are characterized by a steady progression towards death (amyotrophic lateral sclerosis, (ALS) and Lung cancer) and an unpredictable course and sudden death (heart failure). This longitudinal, multimethod study is based on an eclectic conceptual approach, and The Patient Decision Making Framework, that includes the findings of Degner and others. All subjects will be evaluated with quantitative measures and a subset of five subjects in each disease group*

will also be interviewed with qualitative measures. Data will be analyzed to determine the influence of selected demographic, psychosocial, and health characteristics on decision control preferences and the decision control preferences of patients over time. Hypotheses: 1)Patients will exhibit a wide range of control preferences at diagnosis. 2)Control preferences will be significantly associated with demographic and psychosocial/physical health variables. We specifically hypothesize that non-white, non-US born, less educated, more religious patients, and patients with cancer will prefer less control in decision making. 3)There will be a change from more control to less control in patients' decision control preferences as they approach death

Thesaurus Terms:

decision making, emotional dependency, health behavior, health care model, model design /development, terminal patient care

age difference, gender difference, health care policy, health care quality, longitudinal human study, patient care personnel relations, preference, racial /ethnic difference, self help

adult human (19+), behavioral /social science research tag, clinical research, human subject, psychometrics

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